

## The Concepts of Norm and Disease from Scientific to Popularization Discourse

**Abstract:** The ideological implications of the concepts of norm and disease are particularly evident in the area of mental and behavioral conditions. The conflict between the adoption of a statistical model functional to identifying normal behaviour on a quantitative basis on the one hand, and the uniqueness of each person on the other has emerged in research. The discursive representations of these opposing models is particularly interesting, both in specialized texts and in dissemination. This paper focuses on the area of Disorders of Neurodevelopment, analysing in a discourse analytical perspective the innovations included in the 5<sup>th</sup> edition of *DSM* (2013) and their implications for the foundation of a new scientific paradigm centered on personal rather than on clinical outcomes. It also examines examples of popularization of knowledge, showing the contrast between the complex and revolutionary scientific debate and the presentation of individual disorders in the context of web-mediated communication.

Keywords: *discourse analysis, norm and disease, psychiatry, web-mediated dissemination*

### 1. Background, Aim and Method

The ideological implications of the concepts of norm and disease are particularly evident in the area of mental and behavioral conditions. Psychiatry itself is considered a hybrid science, rooted in both the natural and social sciences.<sup>1</sup> Differently from surgery (or other branches of medical science), the object of psychiatric inquiry is filtered through a contextual and cultural approach, while natural sciences can only investigate the relationship between the semantic configurations typical of a certain culture and the human body. Psychiatry deals with behaviour, and behaviours can be evaluated only in the light of constructs that define them. In other words, cultural facts rather than natural phenomena are the object of psychiatry.<sup>2</sup>

Under this perspective, the very idea of disease in psychiatry relies on a preliminary assumption, i.e. the possibility of establishing what is typical (normal) behaviour, and how it can be separated from pathologic deviation. Yet norm is not an absolute and everlasting concept, and therefore the very existence of psychiatric diseases and their classification is the result of a cultural choice. Shared diagnostic guidelines stem from the dominating scientific culture and establish what is right and wrong in a certain historical context. Nowadays, diagnostic tools are largely based on statistical notions, namely the principle of normal distribution and the consequent assumption that significant deviance

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<sup>1</sup> Ivana Marková and German Berrios “Epistemology of Psychiatry”, *Psychopathology*, 45.4 (May 2012), 220-227.

<sup>2</sup> Ciro Ruggerini, Sumire Manzotti and Omar Daolio, “Molteplicità delle aree di conoscenza e ‘punti critici’ (miti) del dibattito attuale sui DSA”, in Ciro Ruggerini et al., eds., *Benessere scolastico negli studenti con DSA* (Trento: Erickson, 2017), 33-54.

from medium value marks the presence of a form of disease. Actually, the bell-shaped model of normal distribution was originally applied to the study of distribution of errors in the measurement of physical quantities, astronomical distances in the first place. Only later was the statistical representation of binomial probability applied to social sciences. In 1835, the Belgian mathematician and astrophysics Adolphe Quételet published an essay, *Sur l'homme et le développement de ses facultés, ou Essai de physique sociale*,<sup>3</sup> presenting a large and original amount of data concerning the development of physical and intellectual human characteristics, aiming to demonstrate that they tend to show a Gaussian distribution. This, according to the author, suggests that it is possible to conceive an actual model of the 'average man', which displays all medium traits, and thus represents all mankind. The new 'social physics' was therefore conceived as the counterpart of astronomical physics, and aimed to discover the laws governing social phenomena and the development of physical and psychological traits of human beings.

The adoption of this model marked an important epistemological turn, as the application of statistical distribution was no longer limited to finding the most correct measure, but was applied to the object of the measurement itself – man in this case. The average is thus assumed to be a real quantity, a natural characteristic of the measured object.<sup>4</sup>

The concept of disease as a deviation from normal behaviour is still at the basis of classifications and diagnostic tools, first and foremost the *International Classification of Diseases (ICD)*<sup>5</sup> and, for psychiatry only, the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. Yet, the most recent version of the latter has promoted for the first time an innovation of this approach, blending quantitative criteria with new dimensional and individual considerations, and thus contributing to a conceptual revolution in mental diagnosis and care.<sup>6</sup> In psychiatry, the ongoing debate on diagnostic criteria and clinical intervention is a symptom of criticism of old categories on the one hand, and, on the other, of the need for new approaches to tackle a large number of problems affecting non-negligible numbers of people.

This epistemological and scientific debate is however scarcely known by the lay public. In contexts of dissemination and popularization, the traditional and consolidated statistical model is still dominant, though usually implicit, and the scope of innovative traits – if mentioned – is not perceivable. The aim of this paper is to investigate how DSM-5 presents some innovations discursively, focusing on the area of Neurodevelopmental Disorders (ND), which is itself an innovation of the last edition of the manual. Attention will then be shifted to popularization, with the analysis of examples of web-mediated communication.

The analysis will be carried out within the theoretical framework of Discourse Analysis (DA). The very concept of discourse, which developed in the wake of Foucault's tradition,<sup>7</sup> at the intersection

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<sup>3</sup> Adolphe Quételet, *Sur l'homme et le développement de ses facultés, ou Essai de physique sociale* (Paris: Bachelier, 1835).

<sup>4</sup> See Lennard Davies, *The End of Normal: Identity in a Biocultural Era* (Ann Arbor: University of Michigan Press, 2013); Roberto Medeghini, ed., *Norma e normalità nei Disability Studies* (Trento: Erickson, 2015).

<sup>5</sup> The current version of ICD (ICD-10, 2016) is available at [icd.who.int](http://icd.who.int). All websites were last accessed on May 31<sup>st</sup>, 2019.

<sup>6</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders DSM-5* (Washington: American Psychiatric Publishing, 2013).

<sup>7</sup> Michel Foucault, *L'Archéologie du savoir* (Paris: Gallimard, 1969) ; *L'Ordre du discours* (Paris: Gallimard, 1970).

between language and society, emphasizes the suitability of different disciplinary approaches, each using its methodological instruments to investigate how discourses contribute to promote certain interpretations of facts and shape reality. Typically, the so-called Critical Discourse Analysis (CDA) approach has brought to the forefront ideologically-sensitive areas of social life,<sup>8</sup> while the French tradition has traditionally focused on the constitutive role of discourse as a source of representation and persuasion.<sup>9</sup>

The linguistic and rhetorical aspects of DA play a fundamental role for the analysis of identification, definition, and classification,<sup>10</sup> which are at the core of diagnostic manuals. Definition is itself an argumentative process,<sup>11</sup> and classification is closely linked to defining choices. In proposing definitions, another important aspect is the discursive position of the enunciator, which can range from full averral to attribution, with varying degrees of commitment.<sup>12</sup> Selection of words, modality and syntactic structures are functional to representing – often implicitly – different viewpoints.

In the following sections, I will examine the diagnostic approach of DSM-5, starting from its discursive representation in the initial parts of the manual, and then focusing on the definition and classification of Neurodevelopmental Disorders (§ 2). I will then analyse the texts of Wikipedia entries concerning Autism Spectrum Disorder (ASD) and Specific Learning Disorders (SLD), with a comparison between the English and the Italian versions. I will also consider a choice of texts taken from highly accessed websites (§ 3). In the conclusions, I will highlight the differences between the scientific debate and its popular representation (§ 4).

## 2. Diagnostic Guidelines

Before examining DSM-5, it is worth introducing briefly the wider background in which it operates. The most comprehensive classification of diseases stems from the World Health Organization, and dates back to 1970. It is the well-known *International Classification of Diseases* (ICD), whose 11<sup>th</sup> version is currently being developed. Its aim is to offer a classification of all pathological conditions, describing both symptoms and aetiology, and to define them on the basis of a coding system. ICD rests on the concept of disease, which is applied both to physical and mental conditions. In 1980 the WHO published an appendix to ICD, which described *Impairments, Disabilities and Handicaps* (ICIDH)

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<sup>8</sup> Ruth Wodak and Michael Meyer, eds., *Methods for Critical Discourse Analysis* (London: Sage, 2001); Ruth Wodak and Paul Chilton, eds., *A New Agenda in (Critical) Discourse Analysis* (Amsterdam and Philadelphia: John Benjamins, 2005); Norman Fairclough, *Analyzing Discourse* (London and New York: Routledge, 2003).

<sup>9</sup> Patrick Charaudeau and Dominique Maingueneau, eds., *Dictionnaire d'analyse du discours* (Paris: Le Seuil, 2002); Donella Antelmi, *Comunicazione e analisi del discorso* (Torino: UTET, 2012); Dominique Maingueneau, *Discours et analyse du discours: Une introduction* (Paris: Armand Colin, 2014); Ruth Amossy, *L'Argumentation dans le discours* (Paris: Armand Colin, 2006).

<sup>10</sup> Marc Angenot, "La rhétorique de la qualification et les controverses d'étiquetage", *Argumentation & Analyse du Discours*, 13 (October 2014), aad.revues.org.

<sup>11</sup> Chaïm Perelman and Lucie Olbrechts-Tyteca, *Traité de l'argumentation: La Nouvelle Rhétorique* (Bruxelles: Éditions de l'Université de Bruxelles, 1958).

<sup>12</sup> James Robert Martin, "Beyond Exchange: APPRAISAL Systems in English", in Susan Hunston and Geoff Thompson, eds., *Evaluation in Text* (Oxford: Oxford U.P., 2000).

and, though considering also contextual factors, basically relied on a linear model based on causal links from impairment (physical or psychological deficit), to disability (incapacity due to the impairment), to handicap (social disadvantage resulting from disability). Impairment as well as disability were interpreted as a deviation from normality, in line with assumptions of *la physique sociale* mentioned above. The second version of ICIDH, known with the same acronym but profoundly revised in its contents, was published in 1997. The new manual focused on the actual capacities of individuals and their interaction with contextual factors, which turned out to be crucial for the classification of health conditions themselves. The subtitle of the manual hinted at this new approach: *International Classification of Impairments, Activities and Participation: A manual of dimensions of disablement and functioning*. In 2001 a further version was approved, with a new title, *International Classification of Functioning, Disabilities and Health*, soon adopted by numerous countries and known as ICF worldwide.<sup>13</sup> In ICF the reference to normality is abandoned, the focus shifts to quality of life and to the interaction between personal characteristics and environmental factors that hinder the full development of the person. This is in line with the renewed concept of disability lying at the heart of the *UN Convention on the Rights of Persons with Disabilities*, adopted in 2010.<sup>14</sup> Actually, the interest in disability issues and the development of disability policies have been crucial in spurring the debate on the themes we are discussing here. The relative value of constructs (such as disease or disorder), the importance of the environment, the emphasis on individual characters, are part of psychiatric culture nowadays, and they are also – albeit timidly – represented in DSM-5.

## 2.1 DSM-5: general approach

The innovative points of the fifth edition of DSM are listed in the Preface, with a special focus on the organization of chapters and the aim to harmonize DSM classification with ICD codes. Behind the re-arrangement there is however a more general concern. Previous classification led to high numbers of cases of co-morbidity, and often resulted in a not otherwise specified diagnosis. This was due to a general structural fault, namely the adoption of excessively narrow categories. As one of the priorities was that of excluding false-positive, a rigid and narrow categorial structure was adopted, and there was a clear divide between different conditions and between them and health. In case of insurgence of contradictory symptoms recourse was made to the concept of co-morbidity.

The organization of DSM-5 is in this respect significantly innovative, as it singles out clusters of disorders and, though preserving a traditional approach to diagnosis proper, leaves room for different interpretations of symptoms and general facts. The authors of the manual explicitly state their policy, thus recognizing the difficulties posed by the adoption of an innovative ideological approach. In the Introduction, they state:

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<sup>13</sup> See Who.int.

<sup>14</sup> See [www.un.org](http://www.un.org).

*Despite* the problem posed by categorical diagnoses, the DSM-5 Task Force recognized that it is *premature* scientifically to propose *alternative* definitions for most disorders. The organizational structure is meant to serve as *a bridge* to new diagnostic approaches *without disrupting* current clinical practice or research.<sup>15</sup>

A concessive structure ('despite') is used to give voice to criticism to previous editions, thus acknowledging the problems of rigid dichotomic categorization. Yet the authors do not take on responsibility for this assumption, but rather admit that time is not ripe for change. The formulation they choose to convey this idea implicitly suggests that scientific research follows a teleological development, which however does not proceed regularly; what turns out to be more correct at a certain moment in time, is not necessarily accepted by the scientific community, and time is often needed for it to be understood, shared, and collectively approved. 'Alternative' options are potentially 'disruptive'. This is in line with Kuhn's view of scientific revolutions.<sup>16</sup> Actually, in psychiatry there are at the moment researchers and clinicians who feel that a 'revolution' is about to occur. Backed by the results of neurobiological research that emphasizes the uniqueness of the human brain not only for its genetic characteristics but also for its acquired neural connections,<sup>17</sup> the insistence on individual characters is leading to a sort of neuro-anthropology, aiming to intertwine different dimensions, in order to give a more realistic view of human existence and of the individual traits of each human being.

The debate on these themes is the leading edge of psychiatric culture today. The DSM-5 manual is half-way between old practice and new epistemological approach. Apparently, it keeps the basic features of a traditional diagnostic tool, based on dichotomic categories; yet it incorporates crucial elements of change, as the presence of clusters paves the way to the disruption of categories themselves and makes the boundaries among categories blurred and uncertain. The dimensional approach, on the other hand, marks the refusal of the Aristotelian concept of category as a homogeneous group, which does not allow a partial or gradual involvement on the part of its members. Innovation is not presented as a revolution, but the message is clear to those who are ready to understand:

The *more* dimensional DSM-5 approach and organizational structure can facilitate research across diagnostic categories by encouraging broad investigations within the proposed chapters and across adjacent chapters. Such a *reformulation* of research goals should also keep DSM-5 central to the development of dimensional approaches to diagnosis that *will likely supplement or supersede current categorical approaches in coming years*.<sup>18</sup>

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<sup>15</sup> DSM-5, 13, emphasis mine.

<sup>16</sup> Thomas Kuhn, *The Structure of Scientific Revolutions* (Chicago: University of Chicago Press, 1962).

<sup>17</sup> Emily Finn et al., "Functional Connectome Fingerprinting: Identifying Individuals Using Patterns of Brain Connectivity", *Nature Neuroscience*, 18 (October 2015), 1664-1671.

<sup>18</sup> *Ibid.*, emphasis mine.

As often happens in scientific revolutions, extreme caution is necessary in introducing a new approach, in order to make it more acceptable. The innovation introduced by DSM-5 is described in relative terms, as ‘more’ dimensional, as if it were a mere question of degree and not a paradigm change. This confirms that the authors do not believe that a total replacement of the traditional approach is possible. They even suggest that the re-arrangement they are proposing is a mere formal question, and choose a low-profile anaphoric encapsulator (‘reformulation’). Yet the direction of evolution is clear, as the new seems destined to parallel and eventually replace the old. Change is presented as inevitable and irreversible.

Another important aspect of the new course is the emphasis laid on cultural issues, which are explicitly dealt with in the Introduction. Recognizing that mental disorders are defined in relation to cultural and social norms and values, the manual recommends that diagnostic assessments should carefully consider contextual elements, which were taken into account also in the development of DSM-5. Section III in particular deals with cultural specificity, and includes tools for cultural assessment. It is explicitly recognized that “the boundaries between normality and pathology vary across cultures”,<sup>19</sup> with immediate consequences on levels of vulnerability and sufferance on the one hand, and coping strategies on the other. Besides its influence on treatment and clinical outcome, the role attributed to culture implies that it is impossible to give a univocal definition of a disorder, and thus contributes to dismantling the idea of a universal statistical norm, which had led to the ontological recognition of the ‘Average Man’.

Yet Section III is not the core of the Manual. It is devoted to “Emerging Measures and Models”, a title that emphasizes its marginal position. The bulk of the manual is Section II, which displays diagnostic criteria that are “well-established measures that have undergone extensive review”.<sup>20</sup> As for Section III, scientific evidence is considered insufficient to support widespread clinical use. Nevertheless, “these diagnostic aids and criteria are included to highlight the evolution and the direction of scientific advances in these areas and stimulate further research”.<sup>21</sup> The idea of teleological development mentioned above is hinted at again. Distinguishing between traditional procedures and innovative tools, the authors confirm the intermediate position of DSM-5, a bridge that should lead from the well-known shores of the past into the promising land of the future.

To sum up, we could say that DSM-5 contains a promise of a ‘paradigm shift’, which however is for the moment not completely fulfilled.

## 2.2 *The cluster of Neurodevelopmental Disorders (ND)*

In Section II of the manual, which contains the actual diagnostic indications, the new cluster of ND is perhaps the most relevant and interesting innovation. ND include intellectual disabilities, communication disorders, autistic spectrum disorders, attention deficit and hyperactivity disorder,

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<sup>19</sup> Ibid., 14.

<sup>20</sup> Ibid., 23.

<sup>21</sup> Ibid., 24.

specific learning disorders, and others. Fundamental criteria for inclusion are the following: genetic or family risk factors, early occurrence, cognitive symptoms corresponding to atypical neurodevelopment, reduced possibilities of remission, frequent co-occurrence of symptoms within the cluster.

The very idea of including in the same group all conditions that occur during development is challenging. Development is different from simple ‘growth’, as it implies a qualitative increase in complexity, and therefore a goal-oriented stance. The manual does not explicitly discuss the concept of development, nor its ethical implications. Yet in the Section devoted to Use of the Manual, the authors, discussing the capacity of traditional validators to identify close homogeneous groups, affirm a general principle: the criteria used to diagnose are selected because of their “clinical utility for the assessment of clinical course and treatment response of individuals grouped by a given set of diagnostic criteria”.<sup>22</sup> In other words, categories are singled out because of their utility rather than their validity. The principle of utility raises further questions, concerning the final aim of the process: Useful for whom? And for what purpose? The importance given to the well-being of the individual all across the manual suggests that, beyond clinical convenience, the concept of utility has to be interpreted in the framework of diagnostic activity and treatment centred on happiness and flourishing of all human beings.

When classifying individual disorders, differences with the previous edition emerge. For example, Autism Spectrum Disorder includes autistic disorder, Asperger’s disorder and pervasive developmental disorder of DSM-4. The re-arrangement of categories aims to make them broader and more flexible, as emerges from the description of individual diagnostic indications. Moreover, the emphasis on scales of severity contributes to enhance the dimensional approach discussed above. This in turn brings to the fore individual traits, which have to be considered also from a functional point of view.

Despite all these interesting innovations, a final consideration is due. The manual consistently uses the word ‘disorder’ and, despite the importance attributed to individual traits, does not suggest that in many cases it would be more correct to talk about ‘differences’. A disorder is characterized by symptoms that result in statistically ‘ab-normal’ behaviour, which in its turn is expression of a form of deficit. Under the perspective adopted by the so-called neurodiversity paradigm, this construct unfairly attributes positive or negative values to different forms of behaviour resulting from different cognitive structures, while each form of human diversity should be equally respected and protected.<sup>23</sup> Neurodivergent behaviour cannot be eliminated, nor should it.

This is actually one of the aporias and, at the same time, challenges of psychiatry: to present in the same manual both disorders and differences, with a consequent confusion between ‘cure’ and ‘care’.<sup>24</sup>

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<sup>22</sup> Ibid., 20.

<sup>23</sup> David Grant, “The Psychological Assessment of Neurodiversity”, in David Pollak, ed., *Neurodiversity in Higher Education* (Oxford: Wiley-Blackwell, 2012), 33-62; Ciro Ruggerini et al., “Neurodiversità e disturbi specifici di apprendimento”, in Enrico Ghidoni et al., eds., *Dislessia in età adulta* (Trento: Erickson, 2012), 92-118.

<sup>24</sup> Ciro Ruggerini et al., eds., *Benessere scolastico negli studenti con DSA* (Trento: Erickson, 2017).



In the light of the debate concerning these aspects of the diagnostic process, the ambiguous half-way position of DSM-5 is confirmed.

The problem emerges with particular evidence in the section devoted to Specific Learning Disorders (SLD). Their diagnostic criteria in DSM-5 include four different aspects:

- 1) the presence of ‘difficulties learning and using academic skills’ (difficulties in reading, comprehension, spelling, calculation, etc.);
- 2) the unexpectedness of the difficulties in relation to age, documented with standardised achievement tests;
- 3) the possibility for the difficulties to remain unobserved during school-years, to emerge only when the demands exceed the capacities (heavier academic workload, demanding timed tests, etc.);
- 4) a differential criterion, i.e. the impossibility to account for the difficulties in terms of presence of “intellectual disabilities, uncorrected visual or auditory acuity, other mental or neurological disorders, psychosocial adversity, lack of proficiency in the language of academic instruction, or inadequate educational instruction”<sup>25</sup>

The fourth point justifies the use of the word ‘specific’ that distinguishes the condition described here. The manual emphasizes the importance of individual learning history, considering also family and educational contexts. SLD have three different manifestations, corresponding to different codes, depending on the compromised ability (reading, written expression, mathematics), and different degrees of severity, which may change during life (the manual invites clinicians to specify ‘current’ severity).

An interesting terminological point deserves comment. Though classifying ‘disorders’, the manual describes ‘difficulties’. Yet the word ‘disorder’ is consistently used in the definition and discussion of diagnostic features. This reveals that the classification of SLD is particularly challenging, as the interaction between the neurobiological and the contextual component is a crucial element in the history of the individual, and the implications of boundaries between normality and deviance are here particularly apparent.

### 3. Popularization

The ND axis of DSM-5 comprises eight different disorders. Some of these are not sub-divided, others include a sub-categorization, which may or may not correspond to different nosographic codes. Specifications in diagnosis are always required, either for the severity or for diversified symptoms, or for both. In this Section, I will take into consideration two disorders, Autism Spectrum Disorder (ASD) and Specific Learning Disorder (SLD), which present a limited differentiation. Diagnosis of the former

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<sup>25</sup> DSM-5, 66-67.



only requires specifications for severity and co-occurrence of some symptoms or conditions. The latter includes sub-codes specifying the presence of different forms of impairment.

I will refer to the essential elements of the DSM-5 presentation, and then focus on texts meant for the lay public. Within the wide choice of texts generated in the computer-mediated environment, I have chosen to analyze Wikipedia entries, as the web encyclopaedia has become the most popular source of information and reference on scientific and medical topics for millions of people worldwide. The phenomenon is extensively discussed in Garzone,<sup>26</sup> who examines the process of generation of Wikipedia entries and their structure, and presents an interesting comparison with traditional encyclopaedia articles.<sup>27</sup>

Beside the relevant Wikipedia entries (both in English and in Italian), I will discuss a few examples of definitions and classifications present on the Internet. In particular, I will consider the most frequently accessed websites, as they appear from a Google query for ‘autism’ (European area).

### 3.1 Autism Spectrum Disorders (ASD)

Within the cluster of the ND, ASD is the third large branch, following Intellectual Disabilities and Communication Disorder. In line with the new course opened up with the 5<sup>th</sup> edition of DSM, diagnostic criteria include evaluation of severity and co-occurrence with other disorders in the cluster. Symptoms, associated behaviour, onset and evolution are described in detail, with great emphasis on functioning, which highly depends on the severity of the disorder itself and on its combination with other problems (such as, for example, intellectual disability). As mentioned above, the description and discussion contained in Section II of the manual apparently have not changed, but the underlying classification criteria are inherently innovative, first and foremost the choice to unify into the same group disorders that were previously classified separately. This makes it possible to recognize common features, and at the same time leaves room for individual analysis.

This innovative trait is consistently mentioned in popularized descriptions of the disorder, though with limited attention for its consequences. On Wikipedia, ASD is defined as “a range of mental disorders of the neurodevelopmental type. It includes autism and Asperger syndrome”.<sup>28</sup> Only after illustration of the main symptoms, its causes and risk factors, the text focuses on DSM-5: “The DSM-5 redefined the autism spectrum disorders to encompass the previous diagnoses of autism, Asperger syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), and childhood disintegrative disorder”. This is a rather technical piece of information, which is given

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<sup>26</sup> Giuliana Garzone, *Specialized Communication and Popularization in English* (Roma: Carocci, 2020).

<sup>27</sup> See also, among the studies analysing the discursive implications of Wikipedia texts, William Emigh and Susan Herring, eds., *Collaborative Authoring on the Web: A Genre Analysis of Online Encyclopedias, Proceedings of the Thirty-Eighth Hawai'i International Conference on System Sciences (HICSS-38)* (Los Alamitos: IEEE Press, 2017); Eva Gredel, “Digital Discourse Analysis and Wikipedia: Bridging the Gap between Foucauldian Discourse Analysis and Digital Conversation Analysis”, *Journal of Pragmatics*, CXV (2017), 99-114; Susan Herring, *Discourse in Web 2.0: Familiar, Reconfigured, and Emergent*, in Deborah Tannen and Anna M. Tester, eds., *Georgetown University Round Table on Languages and Linguistics 2011: Discourse 2.0. Language and New Media* (Washington: Georgetown U.P., 2013) 1-25.

<sup>28</sup> All quotations from the Autism Spectrum page of Wikipedia are accessible at the following address: <https://en.wikipedia.org>.

with no comment, so that non-specialized readers may find it difficult to grasp its actual scope. However, a crucial explanation is then given:

The term “spectrum” can refer to the range of symptoms or their severity, leading *some* to favor a distinction between severely disabled autistics who cannot speak or look after themselves, and higher functioning autistics, such as Temple Grandin, an autism spokesperson.

The concept lying behind the classification (justifying the choice of the word ‘spectrum’) is here presented in a rather simplified way, focusing on the most evident aspect of variation within the spectrum, namely the level of functioning of individual subjects. Yet the distinction is not introduced as a necessary element of diagnosis, since only ‘some’ (presumably, clinicians) adopt this approach. Not only does the enunciator assume no responsibility for this statement, but the attribution is also weak, limited to a minority group (‘some’). Under this perspective, it is not clear what ‘the other’ thinks, and what the ‘spectrum’-based approach implies, if no distinction is made on the basis of actual symptoms and severity. The mention of Temple Grandin, who may be known to the general public for her books and interviews as well as for her 2010 biopic, is a clear element of popularization, which should make it clear that autism is not necessarily a disabling condition, but can co-exist with expectations of adult independent life. The presence of a reassuring element is not isolated in popular contexts, which are often accessed by people (parents, in the first place) who are puzzled and worried by the ‘weird’ behaviour of children who may be diagnosed with autism. In other words, in the case of autism – and also of other ND – technical descriptions tend to incorporate elements of ‘hope’. There is however no explicit discussion concerning the classification of unusual, minority behaviour as an expression of deficit and therefore as a manifestation of a disease.<sup>29</sup>

The Italian version of the Wikipedia entry is similar to the English, but it differs in some aspects that are relevant for the point discussed here. The second half of the introduction is totally devoted to the differences between the DSM-4 and DSM-5 classifications, with detailed indication of the previous and current arrangement. However, these data are presented in a very technical way and with no comment. Therefore it is extremely difficult for the lay public to understand the reasons for the re-arrangement and its significance. This part is a sort of specialized appendix to the previous paragraph, which spells out:

data la varietà di sintomatologie e la complessità nel fornirne una definizione clinica coerente e unitaria, è recentemente invalso l’uso di parlare più correttamente di *Disturbi dello Spettro Autistico* (DSA o, in inglese, ASD, *Autistic Spectrum Disorders*), comprendendo tutta una serie di patologie o sindromi aventi come denominatore comune le suddette caratteristiche comportamentali, sebbene a vari gradi o livelli di intensità.<sup>30</sup>

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<sup>29</sup> Such a discussion can be found on the Temple Grandin website, where “the problem with Labels” is explicitly dealt with ([www.templegrandin.com](http://www.templegrandin.com)).

<sup>30</sup> “given the variety of symptoms and the difficulties in giving a coherent and comprehensive clinical definition, it has recently become common to talk more correctly about Autism Spectrum Disorder (ADS), which includes a whole series of pathologies

The very accurate information concerning the two editions of DSM is not connected to this general introduction, and for the reader it is difficult to understand that the expression ‘Disturbi dello Spettro Autistico’ has actually been introduced in DSM-5. This denomination is presented as a (correct) innovation spontaneously emerging from use, and therefore does not have the authoritative status it could derive from the ethos of the DSM Task Force. Moreover, it is described as an umbrella term including ‘pathologies and syndromes’ that all share the behavioral traits described in the first paragraph, with only quantitative differences. This explanation is rather confusing and inaccurate: on the one hand, the distinction between ‘pathology’ (disease) and ‘syndrome’ may be blurred for non-specialized readers, on the other, differences within the group of ASD are limited to level of severity.

Both the English and the Italian version display a certain degree of vagueness when focusing on the adoption of a new ‘spectrum’ approach, which is limited to ‘some’ of the subjects involved or presented as the result of spontaneous widespread habits. Both versions – albeit differently – are not accurate in describing the nature of the spectrum approach, nor do they explain its conceptual and practical consequences.

On the top-list websites resulting from a Google query for ‘autism’, the spectrum approach is always mentioned, though with some differences. The National Institute of Mental Health, in the section of Mental Health Information defines ASD as “a developmental disorder that affects communication and behaviour”,<sup>31</sup> and refers to DSM-5 to list its symptoms. It adds: “Autism is known as a ‘spectrum’ disorder because there is wide variation in the type and severity of symptoms people experience”. The definition is simple but correct and the explanation clear, indicating that this website is reliable. This is however an isolated exception.

Autism Speaks starts with the following definition: “Autism, or autism spectrum disorder (ASD), refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication”.<sup>32</sup> After incidence estimates, it adds:

*We know* that there is not one autism but many subtypes, most influenced by a combination of genetic and environmental factors. *Because* autism is a spectrum disorder, each person with autism has a distinct set of strengths and challenges. The ways in which people with autism learn, think and problem-solve can range from highly skilled to severely challenged.

The enunciator is here a collective ‘we’. In the context of the whole description, it cannot be interpreted as an addressee-exclusive form, which should refer to experts in the sector. Nor is it actually addressee-inclusive. Rather, it is used as an impersonal form, distributing responsibility of the statement on a non-defined group, and thus suggesting that this is a sort of common opinion. It is

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or syndromes having as common denominator the behavioral traits described above, though with different degrees of severity”, translation mine. Check <https://it.wikipedia.org>.

<sup>31</sup> [www.nimh.nih.gov](http://www.nimh.nih.gov).

<sup>32</sup> [www.autismspeaks.org](http://www.autismspeaks.org), emphasis added.

interesting to note that, in the following sentence, the differentiation of traits is presented as a consequence of the spectrum approach, while it is actually the opposite. In a strict interpretation of this causal link, it is the system of classification that influences the variation of symptoms and severity. This is symptomatic of the difficulties in understanding and, above all, communicating the concept of dimensional categorization, which is actually an oxymoron, combining the need for boundaries with the scalar manifestation of reality. As discussed above, this blended approach is at the core of DSM-5, but the role of the American Psychiatric Association is only mentioned in a footnote, with mere reference to the merging of four previous distinct diagnoses into “one umbrella diagnosis of autism spectrum disorder”.

One last example: on the MedlinePlus website,<sup>33</sup> ASD is defined as a “neurological and developmental disorder”. The emphasis on the neural basis hints at a brain dysfunction that manifests itself during development. The spectrum approach is then introduced: “It is called a ‘spectrum’ disorder because people with ASD can have a range of symptoms”. Here the causal sequence is correct, but the reason for this denomination is reduced to the variety of symptoms, amply described with tones typical of popularization contexts. As in previous examples, the difficulty in disseminating the innovative ideas is evident.

### 3.2 *Specific Learning Disorders (SLD)*

The difficulties in the classification of SLD described above (§ 2.2) are echoed in popularization contexts. The English version of Wikipedia reflects the ambiguities in denomination present in DSM-5. A Google query for ‘Specific Learning Difficulties’ gives no corresponding result in Wikipedia, but shows the entry ‘Learning Disabilities’, which opens with a definition that includes a terminological question:

Learning disability, learning disorder or learning difficulty (British English) is a condition in the brain that causes difficulties comprehending or processing information and can be caused by several different factors. Given the ‘difficulty learning in a typical manner’, this does not exclude the ability to learn in a different manner. Therefore, some people can be more accurately described as having a ‘learning difference’, thus avoiding any misconception of being disabled with a lack of ability to learn and possible negative stereotyping. In the United Kingdom, the term ‘learning disability’ generally refers to an intellectual disability, while difficulties such as dyslexia and dyspraxia are usually referred to as ‘learning difficulties’.<sup>34</sup>

This definition is not fully coherent and explicit. Besides terminological confusion (which reflects actual difficulties and debate in classification),<sup>35</sup> the neurobiological origin of the condition is indicated as the first element, but then ‘several [unspecified] different factors’ are mentioned as possible causes.

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<sup>33</sup> *Medlineplus.gov*.

<sup>34</sup> See *en.wikipedia.org*.

<sup>35</sup> Julian Elliott and Elena Grigorenko, *The Dyslexia Debate* (Cambridge: Cambridge U.P., 2014).

In the second sentence, a quotation is introduced, but no source is specified. The point raised here is crucial, because it marks the divide between ‘typical’ and deviating behaviour, and the text suggests that the absence of typical learning abilities does not equal inability to learn, as it could be possible to learn ‘in a different manner’. However, this interesting concept (which evokes the interaction between personal characteristics and social barriers fundamental to the new interpretation of disability) is apparently applied only to a part of the interested subjects (‘some people’), in a way that reveals a strong prejudice against disability, represented in its traditional negative conceptualization. Thus, a form of dissociation is introduced between the ‘good’ SLD, involving people who are only ‘different’ and should not be classified as ‘disabled’ (an expression that is actually no longer used in official descriptions of disability), and the ‘bad’ ones, who can be said to have a disorder (and possibly a disability). In the final sentence, a further distinction is introduced, which seems to have a limited, purely terminological scope. The distinction between ‘learning disability’ on the one hand, and ‘dyslexia and dyspraxia’ on the other is actually incorrect, as the term ‘disability’ is widely used in association with reading problems also in the UK, and the expression ‘reading disability’ is even considered more appropriate by many researchers and clinicians.<sup>36</sup> Confusion is not limited to the initial paragraph quoted above, as shown by the following excerpt:

Disorder refers to significant learning problems in an academic area. These problems, however, are not enough to warrant an official diagnosis. Learning disability, on the other hand, is an official clinical diagnosis, whereby the individual meets certain criteria, as determined by a professional (psychologist, paediatrician, etc.). The difference is in degree, frequency and intensity of reported symptoms and problems, and thus the two should not be confused.

Here the clinical character of a disorder diagnosis is totally ignored, and the distinction between disorder and disability is therefore based on a misconception. Actually, in the scientific debate around these issues a polynomic-polysemic approach is now spreading, which implies that learning difficulties can be considered ‘both’ disorders and disabilities, depending on the purpose of the classification.<sup>37</sup>

Furthermore, in the second part of the text, the inappropriate information and the distinction introduced in the first part quoted above are ignored, and disorder and disability are interchangeably used as synonyms.

On Wikipedia, the most popular term ‘dyslexia’ is also present. Although both DSM-5 and part of the most recent research avoid this denomination, in popular contexts it is still the most common. Wikipedia introduces it as follows: “Dyslexia, also known as reading disorder, is characterized by trouble with reading despite normal intelligence”, but then describes it as “the most common learning disability”, with no attempt to explain the difference between dyslexia and reading disorder.<sup>38</sup> It is also specified that “some believe that dyslexia should be best considered as a different way of learning,

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<sup>36</sup> Ibid., 178.

<sup>37</sup> Ciro Ruggerini et al., “Neurodiversità e disturbi specifici di apprendimento”, in Enrico Ghidoni et al., eds., *Dislessia in età adulta* (Trento: Erickson, 2012), 92-118; Michael Rice and Greg Brooks, *Developmental Dyslexia in Adults: A Research Review* (London: National Research and Development Centre for Adult Literacy and Numeracy, 2004).

<sup>38</sup> *En.wikipedia.org*.

with both benefits and downsides”. This is in line with the statements concerning learning disabilities we have already examined. The assumption is however presented as a marginal belief (‘some believe’), while it is actually the third point of view included in the polynomic-polysemic approach mentioned above.

On the Italian version of Wikipedia, the entry for SLD (in Italian, *Disturbi Specifici dell’Apprendimento*) can be found, probably because this expression is used in legislation, namely in a 2010 Act (170/2010), which has officially recognized the existence of the problem and thus profoundly changed the approach to it in all educational contexts. As a matter of fact, reference is made to the ICD classification, to DSM-4 (not 5!) and to legislation.<sup>39</sup> On the other hand, the entry for ‘dislessia’ is translated from the corresponding English version, with few differences, which seem to be basically due to misunderstandings. For example, among the various problems a difficulty in pronouncing words is mentioned (‘difficoltà nella pronuncia delle parole’), corresponding to “difficulty in spelling words” in English.<sup>40</sup> The translated text reproduces the source text literally, and therefore the comment on the English version can be extended to the Italian. A further observation: the close word-to-word correspondence extends to the denomination ‘learning disability’, which is translated as ‘disabilità di apprendimento’, an expression which is not currently used in Italy, not even in specialized contexts.

All these considerations suggest that the Italian entry has not been conceived independently, but totally relies on the English source, which is evidently considered to be authoritative and reliable. Actually, both the English and the Italian entries contain imprecise or superficial information, use different terms confusingly, and are unable to give a simple but accurate view of the current scientific and diagnostic debate.

#### 4. Conclusions

Radical scientific innovations are difficult to grasp and accept, even among the experts. The word ‘revolution’ is by no means new in the history of science, but in the last few decades the Kuhnian interpretation of the concept has profoundly influenced the epistemological approach, highlighting the cultural and ethical implications of new scientific paradigms, especially in the social sciences.

Psychiatry, being half-way between neurobiological data and cultural constructs, is the branch of medicine that is most sensitive to the consequences of conceptual change. Researchers in psychiatry are currently discussing the emergence of a new paradigm for the recognition, classification and treatment of mental conditions, aiming to go beyond the concept of disease as deviance from normal (typical) behaviour and focus on the individual traits that make each human being different and unique. This is no minor change, and implies a completely new attitude, requiring at the same time new language and discursive representations.

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<sup>39</sup> *It.wikipedia.org*.

<sup>40</sup> *It.wikipedia.org*.

It is difficult to consolidate this innovative view, and to make it the reference point for shared systems of classification, protocols for diagnosis and treatment, that have relied on different assumptions for a long time. In this respect, DSM-5 is considered a turning point, as it introduces a change in the approach to diagnosis, integrating well-established habits with new considerations, with emphasis on a dimensional rather than categorial classification. Yet the innovation promoted in the manual is still limited and timid. The analysis of its organization and of some crucial passages has confirmed that it is only a first attempt to modify a long-entrenched tradition. Certainly, this choice may stem from the awareness that a more radical change may have led to disruptive consequences, as clinicians in the first place are often unprepared for this revolution in psychiatry.

If experts find it difficult to accept innovation, the lay public is mostly in the dark, and totally unaware of the potential of new approaches. Taking into consideration some popular sources (Wikipedia, in the first place) dealing with two of the most common ND, it is evident that the existence of a divide between norm and disease (or disorder) is taken for granted, thus implying the existence of minority groups comprising individuals who display characters that differ from the norm. One of the most important aspects of DSM-5 is the introduction of the ND cluster itself, which has interesting implications for the elimination of rigid boundaries among disorders, and between normality and impairment. Yet this innovation – if ever mentioned – is not commented on, so that its meaning and its scope remain unknown to the public. Moreover, concepts like cluster or spectrum are introduced with difficulty, and their potential is mostly ignored.

Popularization is generally reluctant to accept new views, above all when they are more blurred and therefore more difficult to communicate. Traditional schemes are usually preferred, and complex debate ignored. Yet the ethical and social consequences of this resistance to innovation can be enormous, affecting the lives of millions of people worldwide.